# COMMUNITY IMMUNIZATION REGISTRIES MANUAL

# CHAPTER IV: OPERATIONS[*]

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# INTRODUCTION TO CHAPTER IV

Operation of a successful immunization registry requires a continuous commitment of resources including staff, funding, and community support. Some may believe that once the hardware and software are in place, fewer resources are needed for routine operation of the registry. In fact, the daily operation of a registry necessitates a permanent reconfiguration in the use of resources. Efforts to gain the trust and confidence of the community and to involve providers in using the registry will need to be maintained and institutionalized. Specific continuous tasks will include establishing telecommunications links, user training and support, data quality assurance, issuing reminder and recall notifications, and monitoring registry daily operations. All of these tasks are essential to ensure the registry meets its original objectives.

A registry is a means to an end. Ultimately, it should operate so as to help reduce the workload of those delivering immunizations. If successful, there should be an increase in the productive time available to providers, resulting in a corresponding rise in immunization coverage levels, particularly for those most at risk of being under-immunized.

Stimulating and sustaining parental and provider participation in the registry requires considerable resources. This chapter addresses the actions necessary for a registry to operate effectively and to fulfill its role in the community. The information provided is based on the early experiences of registries developed by All Kids Count projects and others.

# 1: PROMOTING PROVIDER PARTICIPATION

In order to be effective for providers, immunization registries must contain accurate records on the individuals about whom queries are submitted. Accuracy demands that children's records be updated reliably and reasonably promptly after each immunization is given. Today, most U.S. children receive at least some of their immunizations from the private sector. This appears to be an increasing trend. Accordingly, private providers as well as public health clinics need to be involved and supportive of the local registry.

## BETA-TESTING THE SYSTEM

Computer software, particularly that involving telecommunications links, will likely present some initial operational problems. This unfortunate reality exists despite very careful development and "in-house" testing. One course of action is to implement the basic system first in public clinics before establishing operations with private providers. A few of these clinics, with representative technological capabilities, should be asked to participate in beta-testing[**] the system under "real-world" conditions.

A defined test plan is desirable, including a series of scenarios that tests as many aspects of daily operation as possible. The tests should ensure, at a minimum:

    **o** that the system not accept data outside the permissible parameters (i.e., dates),

    **o** that the security system prevents unauthorized use or work,

    **o** that data are transmitted in each direction without error,

    **o** that messages are sent to the user/sender confirming successful transmission,

    **o** that report-generating functions are operational, and

    **o** that reminder and recall functions work as designed.

A key function of the registry will be assisting outreach activities. Thus, early field testing of the operations, effectiveness, report generating, and reminder/recall functions is critically important. Large sets of test data may be required to conduct such tests. The testing period

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    "Beta-testing" refers to use of an almost fully developed version of a computer system or software in order to detect any problems that occur with real-world use so that these problems can be eliminated from the final product.

should help to identify areas of system use that may be confusing. Testing should also point out where changes may be needed in screen layout, labeling, on-screen "help messages," or in written documentation.

As test cases are run by the user, the success or failure of the system to function as designed should be documented and reported to the registry. When "bugs" (errors) are found and corrected, further testing should be undertaken to verify that the perceived corrections have indeed solved the initial problem without creating a new one. Such follow-up testing should involve "fresh" cases to fully verify proper function. A set of test scenarios that may be useful in other locations should be compiled and maintained. Once the system designer and providers concur that performance is adequate, clinics that have completed testing can begin to enter real patient data. Drawing on the lessons learned at demonstration sites, new training approaches can be developed and additional materials can be obtained or produced. New sites can then be selected for connection, and appropriate training and support scheduled.

Connecting private providers to the registry system may raise different questions. Issues may arise concerning the efficiency of various software interfaces and the compatibility of disparate hardware and communications links. The understanding of the registry system by office staffs or nurses may be different from than that found in public-health clinics. A representative sample of private providers desiring registry participation may be solicited to assist in retesting the system's interface with their offices. Thus, the registry and the clinics may identify problems before embarking on large-scale enrollment of private providers.

Training for private sector users also may require tailoring. Once private provider testing is satisfactorily concluded, it may be worthwhile to develop a demonstration version of the system that operates on a portable computer. This can be helpful when promoting participation with new providers or sponsors and also may be useful for training purposes.

## UNDERSTANDING THE NEEDS OF PRIVATE PROVIDERS

The successful development and implementation of immunization registries requires a basic understanding of private providers' needs, including those of private providers involved in managed-care. If they believe that participating in the registry will be too burdensome or too expensive for the benefits they receive, they may decline to participate or to increase their participation.

Chapters I and III of this manual address approaches to involving private providers in the community planning phases and in the technological decisions related to the registry. The reader is referred to those chapters for a detailed discussion of those topics. The registry's cooperative efforts to facilitate providers' needs must be sustained as operations begin. Substantial time and effort may be required to achieve this and to maintain good

relationships.  In many cases the registry project will be the first time that organizations in the private sector have worked with the public sector.  Preconceived attitudes of each group about the other may need to be addressed.  The registry is an opportunity to show how the needs of private providers are being recognized and met.  Ideally this refreshing revelation will stand in stark contrast to the perception of just another public health program dictating yet more instructions for private providers to follow.

Try to obtain firm data from initial users of the registry to demonstrate how reminder or recall activities result in more children returning to providers' practices and improved immunization rates.  If Health Plan Employer Data Information Set (HEDIS) assessments are done on a provider or plan basis, show how the registry can facilitate the assessment of immunization rates and minimize the intrusion into providers' offices.  Let providers know how the registry can help them document having given the immunization-related services for which employers or Medicaid Managed-Care organizations have contracted.

When explaining the operational aspects of the registry to private providers, emphasize that relationships will be collaborative.  To the extent possible, stress the minimal impact participation will have on the provider's time and the maximum benefits to be realized from participation.  Be careful not to oversell, trying to "do it all."  Let providers know that while you are covering the bulk of the costs and responsibilities, they will need to contribute too.  Their contributions should be in the form of  timely data entry, possible investment in equipment, and promotion of the registry with their peers in the community.

A continuing dialog of feedback and open communications with providers (e.g. through a short newsletter) are critically important.  During the development of the registry, contact with providers will evolve and grow.  Meetings to build support and obtain input will become more involved as the technical plan is developed.  Once system implementation begins, regular meetings with users to coordinate training, provide updates, and obtain feedback will provide an important channel for ongoing improvements.

> The **North Carolina** Immunization Registry (NCIR) project has incorporated ideas from the private provider community since its inception.  The support of the President of the North Carolina Pediatric Society was instrumental in gaining this valuable input.  Due to low market penetration in the state, the managed-care community was not involved in initial stages of NCIR planning.  However, the climate has now changed, and the Immunization Section will be approaching managed-care organizations to become involved with the NCIR in their settings.
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> At the time of this writing, implementation of the NCIR is nearly completed in the public health sector and being piloted in the private sector.  Several Immunization Action Plan (IAP)-funded projects, implemented at the county level across the state,

have paved the way for NCIR to be introduced to the private sector. These projects have focused on immunization follow-up and tracking. They have involved local health department staff members visiting private pediatricians' and family practitioners' offices to review records and conduct Clinic/Provider Assessment Software Applications (CASA) assessments. Trust and confidence have been fostered through these projects and will make the transition to the NCIR smooth.

In addition, early in the planning process, the NCIR successfully lobbied for the introduction of state legislation regarding access to immunization information in patient records. This new law has eliminated barriers to a statewide immunization database and allows for any certified provider to query the database for a child's immunization history. The wording of the amended general statute pertaining to immunizations is detailed as follows:

"Immunization certificates and information concerning immunizations contained in medical or other records shall, upon request, be shared with the Department, local health departments, and the patient's attending physician. In addition, an insurance institution, agent, or insurance support organization, as those terms are defined in G.S. 58-39-15, may share immunization information with the Department. The Commission may, for the purpose of assisting the Department in enforcing this Part, provide by rule that other persons may have access to immunization information, in whole or in part."

The **Houston/Harris County**, Immunization Registry (H/HCIR), Texas, is being developed to link both public and private providers. Implementation is scheduled for early Spring, 1997 and will link the following four immunization providers in Harris County with a population of 1,630,672 residents: City of Houston Department of Health and Human Services, the Harris County Health Department, Harris County Hospital District, and the Texas Children's Hospital. All of the approximately 300 local immunization providers are targeted for inclusion in the H/HCIR. These providers include private solo practitioners, small-group practices, HMOs, and PPOs. Access methods vary to accommodate a spectrum of providers: Some use established immunization registries and have access to electronic technology (batch entry by modem); others have fax capability only. The registry will link with the Texas Department of Health and the Division of Immunization's ImmTrac System to gain access to immunization records of children moving into the community. The registry may then be loaded with data on infants born in Harris County and reported to the Texas Department of Health, Bureau of Vital Statistics. Participating providers will be given a unique identification number for both data entry and browsing access to the immunization database. Each participating child will be assigned an immunization "home" that will have responsibilities for the quality of data entered and for reminder/recall initiation. In response to a query concerning any individual child, data access will be determined by the querying provider's status, whether immunization home or browser. Browser access will be limited to the immunization

record and selected identifying data to provide a unique match. Immunization home status will permit full access to demographic data, the immunization record, and limited vital statistical data such as birth weight and prenatal care.

The **Boston** Immunization Information System (BIIS), Massachusetts, was implemented in 1993 and offers another example of effective private-provider participation. The BIIS is a computerized immunization registry, incorporating a tracking and recall system. BIIS uses a decentralized model in which the participating sites maintain their own immunization database, implements recalls for clients identified as behind, and reminds clients of appointments. Currently the BIIS has over 64,000 children in its database and 28 participating primary health care sites. The Boston Health Department does not conduct well-baby or immunization clinics and has no organic providers. This circumstance raised the initial concern of whether or not providers would participate in the BIIS. The BIIS was developed through the guidance of the Assessment Committee of the Boston Immunization Coalition. This group is a panel of over 90 public and private agencies and individuals who provide services to young children or their families. Involving this Committee was critical to the smooth recruitment and retention of sites. The Committee's initial charge was to design a computerized city-wide immunization registry and tracking system that would be cost-effective and user-friendly. Before selecting software and designing an operational plan, the Committee first identified the providers' expectations for the BIIS. Providers' concerns included the benefits to be gained, trade-offs necessary to make operational changes, and the feasibility of such a system in a clinical setting. Since the Committee represented a broad range of service providers and community groups, many of its members were actually designing a system for their own use. When additional sites were recruited, most new providers already had an understanding of the workings and the usefulness of the BIIS. The Assessment Committee has an open membership and continues to be the guiding force in the implementation, evaluation, and improvement of the BIIS.

In **Chattanooga**, Tennessee, the Hamilton County Health Department took the following approach to solicit participation in its Immunization Registry. When funding was received in 1993 to implement a registry, a visit was made to each pediatric practice to provide information about the registry. Requirements for participation and registry services to be provided to the practice and its patients were discussed. The level of interest in participation was assessed by the Health Department representative during the visit. When needed, the Health Department's Health Officer followed up with the pediatrician to further encourage participation. Registry participants cited tracking services, vaccine history accessibility, and minimal cost as their primary reasons for joining the system. With the current prevalence of managed-care organizations (MCOs), the Health Department is working with these organizations to further promote the immunization registry. A

recent proposal to the largest local MCO requested mandatory registry participation by its providers. Additionally, the Health Department assists the MCOs with immunization surveys by accessing their patients' histories through the registry.

In **Buffalo**, New York, the Pediatric Immunization Program (DrPIP), is located in the Children's Hospital. It is an integrated registry covering the hospital itself, private solo practices, group practices, MCOs, and the public health department. Features proving attractive to a wide spectrum of providers include linkage to billing systems, quality-assurance mechanisms, record-keeping and tracking, report-card producing features, and its user-friendly decision-making facilities.

In **Minnesota**, a survey of 479 of 736 clinics in January 1994 indicated that about 13% of private clinics had a computer-based immunization registry. Since then, MCOs have mobilized to create new registries and upgrade existing registries. Now MCOs play a significant role in the delivery of immunizations.

## USER SUPPORT

Considerable resources must be dedicated to user training and re-training, preparing materials, and providing assistance to providers, without whose participation the registry will fail. A Help Desk may be the best approach to this customer service problem. Duties would include assessing, prioritizing, recording, and analyzing requests, and answering questions. Staff working the Help Desk should be prepared to answer questions of both a technical support nature (software, hardware, and telecommunications problems) and those concerning immunization program support. If the registry's operational territory transcends the local calling area, a toll-free number for the Help Desk would probably be essential. Some registries may enroll providers who lack full electronic access. In these cases the functions of a Help Desk may extend to looking up immunization records in response to phoned or faxed queries. Staffers would need to rapidly provide needed data on the patient's history and immunization status. When not answering calls, Help-Desk staff might be entering data manually for providers lacking a direct computer link.

# 2:  DATA QUALITY ASSURANCE

As early registry projects moved from the planning phase into operations, data quality problems proved to be greater than anticipated.  Some of the problems experienced were:

o   Large amounts of computer time and memory are required to receive batched client data downloads from large providers (e.g. Health Maintenance Organizations).

o   Billing dates, rather than immunization dates, have been recorded in data sets submitted by service organizations used by providers to present claims to third-party payers.

o   Names of infants are sometimes changed within a few weeks after birth.  Immunization registry records created by use of electronic birth certificates may be difficult to match with the child by the time the child is seen for his or her first immunization.

o   Names of children are frequently changed due to adoptions.  Many of these changes have strong confidentiality implications and protection requirements and can result in difficulty matching the child with his or her immunization record.

o   Files on deceased children may not be inactivated, resulting in parents receiving upsetting automatic immunization reminder notifications during a time of great grief.

o   Delays by providers in entering data into the registry may result in parents receiving reminder notices for immunizations already given to their children.

o   Failure of registries to obtain timely out-of-state records about births or deaths may result in months of delay for the inter-state transfer of this information.

o   The lack of a system to obtain immunization data from outside the registry's operational area can result in incomplete data.  This becomes an issue in locations where cross-jurisdictional travel for health care is common.  An example would be travel across a state line where there is a large town, medical facility, or regional birthing center located across the line.  In such cases, special arrangements for data sharing may be needed.

o   The lack of a system for ensuring information is collected about hepatitis B vaccine administered in a birthing center can result in incomplete data.  If this information is not captured by an electronic birth-certificate file received by the registry, it may be

lost. This data is particularly important in the case of children born to mothers who are chronic carriers of Hepatitis B virus, where active follow-up is needed to ensure that the infant completes its series of vaccines.

The necessity of allocating enough personnel to resolve data timeliness or accuracy issues is one of the major lessons learned by currently operational registries. Data quality assurance must receive high priority. Central to the primary reason for registry existence is the amassing of complete immunization records on clients in a single data base. Considerable attention must be given to establishing operational procedures that optimize chances for successfully attaining that goal. The elimination of duplicate records must be assured, first by users, and secondly by registry staff when data are assembled into the registry database.

## CONSOLIDATING MULTIPLE RECORDS ON THE SAME INDIVIDUAL

Duplicate entries will accumulate in the data base over time. Reasons range from human errors during daily operations to records being collected from multiple data bases. The problem grows exponentially with the size of the registry's data base. Even in a single provider setting, it is possible for a second record to be inadvertently created for a established client if names are misspelt or incorrect birth dates used. Such errors initiated by a single participating provider may then be transferred to the registry's data base. However, there may be indications that more than one record exists, leading to a search to identify it.

The problem of duplicate records will be compounded for registries obtaining information electronically from outside sources. The difficulty is that the identification of individuals in data bases lacks precision. Use of a universal identifier is not current practice, although this will change when the new federal requirement for a universal patient identifier is implemented. Currently, Social Security numbers, though usually assigned shortly after birth, are frequently not used as an identifier in a computer data base such as an immunization registry. Moreover, Social Security numbers are not exempt from inaccuracy, misrepresentation, or fraud. Thus, cross-checking multiple data items on individuals to search for possible duplicate records is a necessary part of the daily operations of many users and immunization registries.

### Elimination of record duplication by daily users

Allowing registry users to "browse" for names similar to one entered, when they seek a record by name, promotes day-to-day use. However, registries will tend to have data bases much larger than those of individual clinics. Therefore, the potential is increased for the data base to contain prior, duplicate, or similar records (albeit on other individuals). Users'

experiences with single data bases in single clinics may mean that registry operational procedures are new to them. Administrators may need to encourage users to utilize these new procedures when they search the registry data base. In addition to entering the individual's name, entering parameters such as the date of birth or the mother's name may be useful. The registry computer should be capable of using such data items as both alternate and additional data in locating an individual's record. These added data items tend to improve sensitivity and specificity respectively when searching for prior records. Thus, training the user to routinely enter a small amount of additional data may ultimately greatly reduce the workload of the system administrator in identifying and consolidating duplicate records.

As a security measure, users may be prevented from "browsing" registry records. However, preventing browsing may actually increase the potential that there will be a name-record mismatch. This possibility arises if there is an error in the information entered to initiate the record search. System design and operational procedures should permit a balance between flexible, easy use, detection of duplicate records, and protection of the individual's privacy. "Browsing" security may be increased if the user is permitted to bring up lists of potential record matches. Such a list would not reveal additional personal information on clients except when enough data is entered to indicate a level of knowledge of the individual sufficient to permit access. An example of this approach is provided in the security section of **Chapter III: Technology**.

**Periodic elimination of record duplication by system administrators**

Every registry must have a process for identifying and eliminating multiple entries on the same person. Like the immunization assessment process, solutions are often "homegrown," individually developed, and vary considerably in efficacy. However, good software is commercially available that identifies multiple records on individuals through probability matching. This software can be integrated into batch-uploading applications to match new records with old ones. Yet, the algorithms used by these applications may have unanticipated constraints allowing some duplicate records to remain in the database. Unless manual corrective measures are regularly taken, over time the number of records in the system will grow too large for the number of clients they represent. Manual intervention may be in the form of determining whether pairs of records flagged by the computer truly are duplicates. User correction also includes overseeing the data merging process and correcting the error that led to a mismatch in the first place. A determination may be required on which of two similar names is correctly spelled, or which is the correct date of birth. Long-term storage of presumably duplicate records is advisable in the event a problem ensues after the merge, and a need arises to reconstitute or to refer to the original data.

When multiple records are consolidated into one immunization history, the process needs to

prevent the same immunization event from being recorded more than once.  Each registry also will need rules on how to define the immunizations within a series (dose 1, 2, 3, etc.) and to allow for valid time intervals between doses.  In some cases it may be found that individuals have been given extra doses of vaccine.  In these cases errors probably result from an ignorance of the recipient's prior history.  Further, immunizations given within a time interval that is too short between doses will need to be identified and discounted during the merge process.  Errors also may result from incorrectly recording or transmitting the immunization date.   For example, if data are obtained from a physician reimbursement service, the billing date rather than the service delivery date may have been entered. Providers, relying upon the supposed validity of their own records, may be concerned to learn that the registry has invalidated one or more immunizations.  Establishing consistent and thoughtful policies and procedures for dealing with providers about these points may be helpful.  An example of the importance of allowing resources for data quality assurance follows:

> **In San Bernardino county**, California, with a birth cohort of approximately 30,000, 10 to 15 person hours are spent each week reviewing data.  When a new provider first begins sending data, even more hours of human intervention are needed.

# 3: USING THE REGISTRY FOR OUTREACH ACTIVITIES

Immunization registries should allow targeting of outreach activities toward groups at greatest risk of under-immunization. These target populations may be dispersed across a state, living in one or more counties, or from a particular sub-population. They may be easily defined by one or more fields in the data base, such as for clients of an individual practice or clinic. All but the most basic immunization registries should collect and use appropriate data elements to **remind** clients of immunizations due and to **recall** those who have missed immunizations. Reminder/recall methods include:

o   postcards and  letters,

o   telephone auto-dialers or personal phone calls, and

o   home visits.

As many public health and assistance programs have similar goals and serve the same population, consideration should be given to making the reminder/recall program a coordinated effort. The system might then be used as an outreach mechanism for multiple programs by including information about WIC, immunizations, AFDC, and others in a single mailing.

In addition to reminding clients about immunizations or other health-related programs, outreach activities should consider positive feedback and reinforcement for parents whose children have successful immunization histories. The experience of a Savannah, Georgia registry in this area is provided on page 16.

## ACCURACY OF ADDRESSES OR PHONE NUMBERS

Regardless of the outreach method used, success ultimately depends upon the quality of data in the registry. As described in the previous section, maintaining an up-to-date reminder list that excludes the names of children who have been adopted, left the family, or who have died, may be quite difficult. However, it is very important that it be done. Contacting the family of a deceased child about immunization is extremely stressful to the parents and embarrassing to the registry staff. Further, a blunder of this nature creates an image of a dysfunctional, impersonal, and uncaring system. To avoid difficulties in this sensitive area, good communication between users and data suppliers is essential. Users must understand and consider the system's limitations. Their cooperation must be obtained in expediting the information needed to keep the data base accurate. However, there will be unavoidable lag

times in receiving death records, or in adoptions being completed.

Keeping accurate addresses for children who move may be difficult as well. In San Bernardino, California, 10% of the reminders sent by the health department to mothers of 2-month-old children, based on birth-record addresses, are returned marked "undeliverable." About six weeks elapse between the time the reminders are sent and when the undeliverable ones are returned.

## PARAMETERS OF OPERATION

The planning of outreach activities involves setting certain operational policies. Experimentation and evaluation will reveal which approaches are more cost-effective for the populations served. The following operational parameters will need defining by the registry:

**Mail:**

o   How many times shall reminder/recall notices be mailed?
o   What procedures will be used to log bad addresses?
o   Are procedures adequate to ensure the most up-to-date addresses?
o   Which type of mailing should be used (e.g., first class [for return of non-deliverable mail] versus third class [for lowest costs])?

**Phone:**

o   How many times does it redial?
o   What procedures will be used to log bad numbers?
o   What day of the week and time of day should calls be placed?
o   Are procedures adequate to ensure the most up-to-date phone numbers?
o   What is the cost of operations?

**Home Visit:**

o   How many times should visits be attempted?
o   What procedures will be used to log bad addresses?
o   What are appropriate days of the week and times for visits?
o   Are procedures adequate to ensure the most up-to-date addresses?
o   What is the cost of visits?
o   Who should be responsible for conducting visits?

In many localities consideration is necessary regarding  the most appropriate language to

be used in written and spoken messages. Also, thought should be given to who is the best person to record a spoken message. Data elements have been defined in **Chapter II: Confidentiality** that automatically select the clients' preferred languages. Use of messages recorded by local celebrities can make them more appealing and effective. Before starting the activity, focus groups might be used to evaluate the best types of messages. As part of evaluating the outreach process, target audiences might be queried regarding the impact various messages have on them.

Some examples of approaches to automating reminder or recall functions include:

In **Arizona** a test of auto-dialers in an area with a large Hispanic population appeared effective when an introduction was quickly given in English and Spanish, advising that the entire message would then be given in both of these languages.

In **San Diego**, California, preliminary indications are that SE Asian immigrants were more likely to take note of a post card with an English message. Official looking post cards suggest the mailing contains important information that should be taken to someone who could translate it.

In **Savannah,** Georgia, the reminder phone calls initially used the voice of the Director of the local Department of Health. The rate of hang-ups was high and the rate of return for appointments was low. These reminders were being used in an area where most of the community were of the same ethnic origin. A local TV anchor person of the same ethnicity was asked to record the reminder message. It was an overwhelming success. Parents were eager to tell their neighbors that a celebrity had called them, and became energized about their child's immunizations. The Savannah program also used the registry data to identify families where 2-year-old children had completed their immunization series. Those families were sent notifications that a special party was being given to reward them. As news of the party was spread among children, those not yet up-to-date were given an incentive to complete their series so they too could participate.

## IDENTIFYING THE SOURCE OF NOTIFICATIONS

An agreement is needed between the registry and each private provider or organization concerning the cited origin of reminder/recall notices. The question needs to addressed of whether the mailings will be identified as coming from the registry, the provider, or some other registry-supporting entity. Agreement in this area may not be simple to reach. For example, it may not be clear who should be identified as the source of mailings to private providers' patients who receive at least some immunizations in a public clinic. Although he or she may not be the source of immunizations, the provider may wish these patients to retain

a sense of relationship with the provider and not the public health department, as the person ultimately responsible for their health care,. A variety of solutions may be needed in any one community. For example, the registry computer's programming and the telephone auto dialer must afford the option of giving out provider-specific messages if needed. When providers insist that their patients be contacted only by their office, the registry can offer to provide phone numbers or addressed mailing labels from the data base.

## OPTING-OUT PROVISION

Most parents seem to appreciate reminders of immunization appointments. However, some parents may believe that the health department is acting like "Big Brother," or they may be concerned about registry data being linked to other undisclosed databases. Registries should respect and accommodate the wishes of those who decline to participate or who decline to receive planned communications.

## FUNDING REMINDER RECALL

Reminder/recall systems should enhance the effectiveness of medical services rendered by providers as well as the numbers of clients seen. As a result, providers' revenues should increase. Consequently, a degree of cost-sharing may be in order between registries and providers. Costs incurred by the registry include the staff and equipment necessary to develop an automated system, an ongoing effort to purify address and phone number data, and postage for mail reminders. In a small community, there may not be any telephone use charges. Some examples of cost-sharing approaches are provided in **Chapter I, Planning**.

# 4: SYSTEM MAINTENANCE AND SECURITY

In addition to the efforts necessary to enroll providers, sustain registry connectivity, and monitor data and control its quality, yet another major task needs to be undertaken. Resources and operational procedures must be put in place to maintain the overall integrity of the system and to allow for its enhancement as technology evolves.

## DATA BACKUP AND DISASTER RECOVERY

At regular intervals the adequacy of the data backup system and disaster recovery plan should be reviewed and tested by a simulated emergency. In systems with distributed data bases, the registry staff needs to communicate with providers' staffs to ensure they are maintaining back-up data. By so doing, data recovery will be facilitated when the inevitable problem occurs: the "crash" of a hard-disk or some other major data storage medium.

To be prepared for problems, telephone numbers should be readily available for contacting a system administrator after business hours. Maintenance documentation on the system should be kept current. Repair contracts and other product support agreements should be kept up-to-date and in effect. Arrangements to replace failed components on short notice should be an integral part of the technical support agreement.

> In **Nevada** the AKC Immunization Registry has taken the following measures to safeguard proper maintenance, back-up, and security. Maintenance is provided by the central site in Carson City. The second largest health district, Washoe County, is connected to the registry via Integrated System Digital Network (ISDN). The 17 rural community health nursing sites' data bases can be accessed through 28.8K dial-up modems. This communication network allows access for software upgrades and troubleshooting from the central site by the AKC project or the software vendor. Maintenance problems that cannot be solved remotely may require an on-site visit from the AKC computer-system administrator. In Washoe County data is transferred nightly to the central site via the ISDN connection. Each of the rural county sites has tape back-up capacity and back-up is conducted daily. The tape back-up will be augmented when each of the rural nursing sites begins nightly data transfer to the central site via modem. System security is provided by Novell Netware. The use of passwords and limited access to programmable software functions has also been incorporated into the registry software. For added security, all system hardware at the central site is in a locked, coded room. The Nevada AKC immunization registry has not experienced security issues with private providers whose system access is limited to their own needs.

# EQUIPMENT (HARDWARE, SOFTWARE, COMMUNICATIONS)

Advances in technology occur continually and have the potential to improve the performance of registries.  It is important that registry staff stay abreast of developments and innovations in the field.  Occasionally it will be necessary for staff members to attend conferences or training for specific products.  Expenses in this area should be anticipated as well as for the periodic procurement of contemporary software and equipment that can:

o   upgrade computer memory and speed to reduce delays or accommodate more users,

o   expand solid media data storage capacity (for the archiving of old records and to provide faster access to current ones as numbers increases),

o   upgrade software to increase its functional capacity, ease of use, and reliability, and

o   improve the capacity or speed of telecommunications, such as installing faster modems.

Regular meetings should be scheduled (e.g. every 3 months) for the entire team operating the registry to discuss if and when these expenses may be needed.  It should be kept in mind that delays are frequently encountered when placing requisitions for information technology products through state or local governments.  Early planning is strongly encouraged.  Replacing a hardware component may necessitate software and/or communications equipment reconfiguration.  Significant changes to the system will require much thought.

Also bear in mind that the computer in a provider's office is used for multiple purposes.  Software changes or upgrades should not be imposed by the registry if they might compromise or conflict with non-registry functions of providers' computers.

# 5:  MONITORING PERFORMANCE

## MEASUREMENT OF PROCESS AND OUTCOME INDICATORS

**Chapter I, Planning,** indicated that the registry planning process should include strategies for assessing how well the plans are executed (**process**), and how much benefit is achieved for users and the community as a whole (**outcome**).  Important registry outcomes to measure would include changes in immunization rates in target populations, the effect on work efficiency in providers' offices, and the impact on parental commitment concerning their child's immunizations.  These, and any additional indicators of interest, should be set out in a written evaluation plan that addresses the questions:

o    What activities or outcomes will be monitored?

o    Who is responsible for performing the monitoring?

o    What methods will be used to collect information?

o    How frequently it will be collected?

o    What sources of data will be used to collect the information?

o    To what baseline data will findings be compared?

See **Chapter I, Planning,** for further information on designing evaluation and monitoring.

Assessment findings may be presented to the registry's Advisory Committee, private providers, partners with whom information is being shared (WIC or the Vital Statistics Registrar), and other registries.  Feedback  from such review groups can be used to determine what corrective actions might be needed in the objectives, methods, or assessment activities.

## ASSESSING OUTCOMES

### Numerical targets

To meaningfully gauge achievements, registry outcomes should be quantitatively measurable.  For example, the CDC has proposed that a suitable target for measuring immunization registry development is the change in the percent of children between 12 to 23 months of age on whom the registry maintains active immunization records.  Omitting children between birth and 11 months of age from the outcome measurement is intended to overcome the

potential problem of unreliable data on children in the first few months of life. Thus, success is not measured on the basis of the total number of established records. Subset target populations may be selected for assessment measurements if the need exists to determine results in specific socio-economic or ethnic groups. The CDC proposal provides a uniform means for tracking registry development and implementation across the country. It does not address immunization coverage rates.

However, population-based coverage rates remain vital pieces of statistical data. This information is necessary for local managers and users to assess their progress toward the ultimate goal - 90% of children up to 2 years of age fully immunized by the year 2000. Additionally, the ability of the registry to provide coverage rates on population subsets may be an important tool in quantifying the registry's success.

**User satisfaction**

Measuring user satisfaction is another good assessment of registry operational effectiveness. Users satisfaction is not static. As experience is gained with the system, user expectations will change. Users may request various additional applications, reports, or performance enhancements. Requests for performance improvements may stem from legitimate "bugs" in the system. Another user satisfaction improvement might be reducing the number of key strokes necessary for an operator to enter data.

A systematic approach to addressing users' needs includes recording Help-Desk requests for assistance and surveying users to determine the level of their satisfaction with responses received. It is critical to know if providers believe the registry delivers the promised services in return for the workload and expense invested, and if they believe the registry is helping to meet the immunization goals of the community. It will also be helpful to know the attitudes of clients towards the registry. It should be ascertained whether or not clients believe they are benefitting without undue interference with their privacy.

**Cost-benefit**

Economic evaluations need to be made to determine that registry operating costs are being kept to the minimum consistent with quality. Further, it needs to be determined that the increased coverage benefit is affordable from the community's perspective. A standard methodology for performing these cost/benefit analyses would be useful. The data required should not make the analyses too complex to conduct at the local level. Such analyses might be useful in selecting targets for studies to determine the cost for each additional child who is current on his or her immunizations by 2 years of age. There are many variables that need to be taken into account. Knowing the level of expenditures, numbers of providers involved, and the percent of children by age group with active records, will help in understanding the

true costs of registry development and operation.

## ASSESSING PROCESS

### Timeliness of data

One indicator of a successful process is the lack of undue delay between administering immunizations and recording them in the registry. Inordinate delays in recording immunizations may result in inappropriate vaccinations being given, or parents disregarding legitimate reminder notices.  The latter may occur if parents have previously experienced "false-alarm" reminders for immunizations they know were recently given to their child.  Parents then may become desensitized to all reminder/recall notifications. Monitoring users may indicate if additional training is required.

### Use of the data

Frequency of system use is a solid indicator of its perceived importance.  The knowledge, attitudes, and practices (KAP) of providers' staff members may be evaluated to learn which providers are frequent users and which rarely use the system.  Provider sites that one might expect to be heavy system users, may not prove to be so.  In such cases it is prudent to look for problems requiring resolution.  Another indicator that the process is working is the ability to perform outreach functions such as mailing reminders. Several outreach activities are amenable to measurement and could be linked to outcome analysis, such as the impact reminders have on recipients' immunization attendance rates.

Some management issues might also be addressed in the assessment process.  Analysis of issues such as whether the registry permits providers to know the coverage rates in their practices may be helpful.  Determining whether the system improved efficiency of operation for the provider may be possible.  One example of improved provider efficiency would be if  outreach activities successfully bring delinquent immunization clients back to the provider.  In this regard, registry data can be directed to evaluate a particular target community or a particular provider or managed-care organization.

# 6: SUMMARY OF 30 KEY ACTION STEPS: OPERATIONS

## Promoting provider participation

1. Develop training materials to include a draft user manual with step-by-step instructions, written in plain English, and without "technical jargon."

2. Beta-test the system at representative public and private demonstration sites. Correct the deficiencies noted and update the user manual accordingly.

3. Develop a portable demonstration version of the registry's immunization-data tracking system to use when seeking participation by new providers, or when seeking sponsors.

4. Initiate a Help-Desk system to provide continuous user support.

5. Implement a tracking system to ensure that users have installed the current version of the software and have been trained in its use.

6. Obtain data from test sites showing how reminder/recall functions improve immunization coverage rates. Improved coverage rates enable population-based assessments to be done with a minimum of government intrusion into the private providers' offices.

7. Show providers how population-based assessments can be used to document the provision of services to employers or Medicaid Managed-Care organizations.

8. Provide feedback and communications to providers on registry development and issues.

9. Seek assistance from providers in promoting the registry with their peers.

**Data quality assurance**

10. Provide adequate resources for monitoring and correcting the quality of data.

11. When receiving batch data submissions, run standard computer-error checks to screen for errors such as immunizations reported as given before the date of birth.

12. Create and frequently run a software application that locates and displays potential duplicate records, whether in the central registry database, or in distributed databases.

13. Assign specific staff members to review potential duplicate entries.

14. Ensure that the merging process includes creation of backup copies of the original records. Take care that the merging process correctly shows a client's total immunization history. Take into account issues such as dose number or dose interval that might be impacted by the merging process.

**Outreach activities**

15. Establish procedures to identify persons included in the registry who have died or been adopted, and inactivate or update their records, as appropriate.

16. Seek the cooperation of neighboring jurisdictions in obtaining data on births, deaths, or relevant immunization information.

17. Train registry staff how to handle complaints following erroneous notifications being sent to parents of deceased children, or for immunizations not yet reported to the registry.

18. Decide whether to give physicians the option of mailing reminders indicating the registry as its source, or citing the provider as the originator of the notice.

19. Determine the best written or spoken messages for different target groups in the community and use language-specific or multi-lingual notifications as appropriate.

20. Give parents the option not to receive reminders.

21. Encourage parents to listen to auto-dialer messages about immunizations.

22. Ask providers to consider cost-sharing for notification systems.

**System maintenance and security**

23. Review procedures to be followed by registry staff and users for backing up data and for disaster recovery. Consider carefully their full implementations.

24. Budget for registry staff to attend technology training to keep their skills current.

25. Ensure warranty and emergency repair documents are current and available.
26. Plan well in advance to be able to purchase hardware and software upgrades.

**Monitoring performance**

27. Prepare an evaluation plan that provides meaningful, qualitative, and quantitative information about the registry's performance from the outset.

28. Review regularly with an advisory committee whether the original immunization project mission, goals, and objectives are being met.

29. Target a "pocket of need" for the registry to track. Evaluate immunization levels in that area and the effectiveness of the registry's reminder/recall program.

30. Survey the levels of provider and client satisfaction periodically. Obtain their input and ideas about improvements they would like to see.

# APPENDIX IV-1

## List of persons to contact about immunization registries in state or other projects receiving grant funds from the National Immunization Program, CDC

CENTERS FOR DISEASE CONTROL AND PREVENTION
NATIONAL IMMUNIZATION PROGRAM
**PROGRAM MANAGERS AND IMMUNIZATION INFORMATION SYSTEMS
COORDINATORS**
May 9, 1997

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|---|---|
| Alabama Department of Public Health<br>State Immunization Division<br>201 Monroe Street<br>P.O. Box 303017<br>Montgomery, Alabama  36130-3017<br>ASYNC #:  329-8260<br>FAX #:  (334) 206-2044 | Gary F. Higginbotham (PHA)<br>PHONE#: (334) 206-5023<br>Harold R. Brown, Jr.,<br>SIIS Program Manager |
| Alaska Dept of Hlth & Social Svcs<br>Immunization Program<br>3601 C. Street, Suite 576<br>P.O. Box 240249<br>Anchorage, Alaska  99524-0249<br>ASYNC #:  329-8302<br>FAX #:  (907) 562-7802 | Laurel H. Wood (PROJ)<br>PHONE #:  (907) 561-4406 |
| Arizona Department of Health Services<br>Vaccine Preventable Disease Section<br>Immunization Program<br>3815 North Black Canyon Highway<br>Phoenix, Arizona  85015-5351<br>ASYNC #:  329-8292<br>FAX #:  (602) 230-5817 | Sandra L. Loesser (PROJ)<br>PHONE #:  (602) 230-5852<br>Mike Popovich, IIS Manager/Contractor<br>PHONE# (602) 230-5852 |
| Arkansas Department of Health<br>Immunization Program<br>4815 West Markham<br>Stop #48<br>Little Rock, Arkansas  72205<br>ASYNC #:  329-8275<br>FAX #:  (501) 661-2055 | Karen Fowler (IIS Coord)<br>PHONE #:  (501) 661-2720<br>Karen Mason (Project Mgr) |

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Connecticut State Dept of Health  
Department of Public Hlth & Addiction Svcs  
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Phil Mollison -State  
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Delaware Dept of Hlth & Social Services  
Imm. Pgrm/Div. Of Public Health  
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Bill Baker (Alternate)  
Kathleen Russell (Alternate)  

Florida Department of Health and  
Rehabilitative Services  
1317 Winewood Blvd., Bldg. 2, Rm 268  
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Bill Spencer -SIIS Coord  
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Delaine Sans
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Bureau of Disease Assessment, VPDP
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Mark Shields, (IIS Coord.)


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John Pease, Imm Systems Mgr


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P.O. Box 2816  
Majuro, MH  96960  
ASYNC #:  329-8298  
FAX #:  011-692-625-3432  

Nora Kilmaj-Saul (PROJ)  
PHONE #:  011-692-625-3480

Federated States of Micronesia  
Division of Health Services  
Immunization Program  
P.O. Box PS 70, Palikir  
Ponape, FM  96941  
ASYNC #:  329-8295  
FAX #:  011-691-320-5263 or 5500  

Kidsen Ishop (PROJ)  
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Department of Public Health and  
Environmental Service  
Commonwealth Health Center  
Commonwealth of the Northern  
Mariana Islands/P.O. Box 409, CK  
Saipan, MP  96950  
ASYNC #:  329-8299  
FAX #:  011-670-234-8930  

Norma Sotto-Cepeda (PROJ)  
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Bureau of Health Services  
Immunization Program  
Republic of Palau  
P.O. Box 100  
Koror, RP  96940  
ASYNC #:  329-8301  
FAX #:  011-680-488-3115  

Rosemary M. Kiep (PROJ)  
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# APPENDIX IV-2

**List of persons to contact in demonstration immunization registry projects funded by foundations**

## ALL KIDS COUNT
## GRANTEE CONTACT LIST

### ARIZONA

Arizona Department of Health Services
Disease Prevention Services
3815 N. Balck Canyon Highway
Phoenix, AZ 85015

**Terry Hughes**
Phone: 602-230-5852
Fax: 602-230-5817
E-Mail: thughes@hs.state.az.us

**Mike Popovich**
Phone: 520-325-3185 (Tucson Office)
Fax: 520-325-3073     DETRO
E-mail: mpopovi@hs.state.az.us

### BALTIMORE

Baltimore City Health Department
Immunization Bureau
4 S. Frederick St., 3rd floor
Baltimore, MD 21202

**John Lamoureux**
Phone: 410-396-4457
Fax: 410-396-3965
E-Mail: lamo102w@wonder.em.cdc.gov

### CHATHAM COUNTY (SAVANNAH)

### CLEVELAND

Cleveland Department of Public Health
c/o The Federation of Community Planning
The Rockefeller Building
614 Superior Avenue, Suite 300
Cleveland, OH 44113

**Nancy Heineke**
Phone: 216-781-2944, Ext. 523
Fax: 216-781-2988
E-Mail: heineke@fcp.org

### DETROIT

Detroit Health Department
c/o Greater Detroit Area
Health Council, Inc.
Penobscot Bldg., Suite 4100
645 Griswold St.
Detroit, MI 48226-4209

**Ronald L. Beford**
Phone: 313-963-4990
Fax: 313-963-4668
E-Mail: rbeford@msms.org

**Stella Bayless**
Phone: 313-876-4334
Fax: 313-876-0177
E-Mail:  bay1102w@wonder.em.cdc.gov

Chatham County Health Department
PO Box 14257
2011 Eisenhower Drive
Savannah, Ga.  31416-1257

**Marianne Pappas**
Phone: 912-356-2679
Fax: 912-356-2919
E-Mail: mkpl@ph.dhr.state.ga.us

**Bao Hoang**
Phone: 310-794-6961
Fax: 310-794-6963
E-mail: chain@ucla.edu

## MILWAUKEE

Milwaukee Health Department
841 North Broadway
Room 112, Municipal Building
Milwaukee, WI 53202

**Holly Stansell**
Phone: 414-286-8034
Fax: 414-286-8174
E-Mail: hstans@ci.mil.wi.us

## MISSISSIPPI

Mississippi State Department of Health
PO Box 1700
2423 North State Street
Jackson, MS 39215-1700

**Liane Hostler or Virginia Mayes**
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Fax: 601-354-6006
lhostler@unite.msdh.state.ms.us
vmayes@unite.msdh.state.ms.us

## LOS ANGELES

Los Angeles Child Health and
Immunization Network (CHAIN)
10920 Wilshire Blvd. Suite 1103
Los Angeles, CA 90024

## NASHVILLE

Metropolitan Health Department of
Nashville and Davidson County
311 23rd Avenue, North
Nashville, TN 37203

**Mary Fowler**
Phone: 615-340-5667
Fax: 615-340-5665

## NEVADA

Nevada Department of Human Resources
Health Division
505 E. King Street, Room 304
Carson City, NV 89710

**Robert C. Salcido**
Phone: 702-687-4800
Fax: 702-687-4988
E-mail: salc100W@wonder.em.cdc.gov

## NEW JERSEY

New Jersey Comprehensive
Immunization Program
Department of Pediatrics
UMDNJ-RWJMS
One Robert Wood Johnson Place, CN-19
New Brunswick, NJ 08903-0019
**Barabara Goun, Ph.D.**
Phone: 908-235-7904

## MONTEREY

Monterey County Health Department
1270 Natividad Road
Salinas, CA 93906-3198

**Robert Melton, MD**
Phone: 408-755-4500
Fax: 408-757-9586

## NEW YORK CITY

Medical and Health Resarch Association
of New York City, Inc.
93 Worth St., Rm 714
New York, NY 10013

**Gerry Fairbrother, Ph.D. or**
**Amy Metroka**
Phone: 212-676-2320
Fax: 212-965-9194
Email for Gerry Fairbrother:
  hend101w@wonder.em.cdc.gov
Email for Amy Metroka:
  metr100w@wonder.em.cdc.gov

## NORTH CAROLINA

North Carolina Dept of Environment
Health and Natural Resources
Immunization Section
1330 St. Mary's St., Rm 405D
Raleigh, NC 27611-7687

**Mary Beth Lister**
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Fax: 919-715-6781
Email: marybeth_lister@mail.ehnr.state.nc.us

## ORANGE COUNTY, CALIFORNIA

Fax: 908-235-7345
Email: goun@umdnj.edu

**Susan Slakowitz**
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**Ruth Gubernick**
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Email: gubernos@umdnj.edu

## PHILADELPHIA

Philadelphia Dept of Public health
Division of Disease Control
500 S. Broad St
Philadephia, PA 19146

**James Lutz**
Phone: 215-685-6748
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Email: lutz101w@wonder.em.cdc.gov

## RHODE ISLAND

Rhode Island Dept of Health
Room 106, Cannon Bldg.
Three Capital Hill
Providence, RI 02908-5097

**Kim Salisbury-Keith**
Phone: 401-277-1185, x 190
Fax: 401-277-1442
Email: sali100w@wonder.em.cdc.gov

## RICHMOND

Richmond City Health Dept.
Marshall Plaza Building
900 East Marshall St., B-Level

County of Orange Health Care Agency
Public Health
1725 W. 17th St.
PO Box 6099
Santa Ana, CA 92706

**Tony Edmonds**
Phone: 714-834-7979
Fax: 714-834-8051

## SAN DIEGO

County of San Diego Dept of
Health Services
3851 Rosevcrans St.
Mailstop -P511X
San Diego, CA 92110

**Brenda Jo Robyn**
Phone; 619-692-8482
Fax: 619-692-6619
EMAIL: bobyn@mail.sdsu.edu

## SAN LUIS OBISPO

San Luis Obispo County
Public Health Dept.
2191 Johnson Ave.
San Luis Obispo, CA 93401

**Henry Herrera**
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Fax: 805-781-5543
Email: hherrera@co.slo.ca.us

## SANTA BARBARA

County of Santa Barbara Health Care Services
Immunization Project

Richmond, VA 23219-1800
Phone:   804-780-4147 // 804-698-3162
Fax: 804-783-8257

## SAN BERNARDINO

San Bernardino County Dept of
Public Health
799 East Rialto Ave.
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**Sarah Mack**
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## SNOHOMISH/WASHINGTONSTATE

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6101 200th St. , SW Suite 205
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2115 Centerpoint Parkway
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**Mary Carol Magee**
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## SANTA CRUZ

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PO Box 962
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